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Mentoring with Disability Awareness

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Abstract

Disability Awareness encompasses the understanding of Disability Culture, Effective Communication, and Etiquette as it relates to the various members of the Disability Community. Disability Culture will touch on the interaction of the broader community that influenced individuals with disabilities and how their shared experiences and the history of the laws have affected this large segment of American Society. Effective Communication is an essential component for the different members of the disability community. The effectiveness of communication will involve what is critical to know to provide effective mentoring services for staff and students in the educational or employment sectors. One important aspect of Disability Awareness is that it will provide a background of crucial information required to be an active mentor.

Disability Culture and Community

To understand Disability Culture, one must first understand the majority, non-disabled culture that formed the circumstances and conditions bringing the Disability Culture into being and becoming a community in its own right. Disability history, activism, and the community's view of itself as a culture created the Disability community today. This paper will highlight some examples of the Disability community's development from ancient times to the twenty-first century. It will create an awareness of the Disability community.

Disability History

History defines people with Disabilities based on the experiences of those who have gone before us. Thus, they created a society in which future activists can continue to make changes for the better. From primitive times to this contemporary age, it shows that people with disabilities have been resilient in creating change that lay the groundwork for a better future. Nielson (2012) and Drum (2009) provide valuable insights based on research:

> In primitive times, people with disabilities died through natural causes, neglect, or at the hands of members of tribal societies. During the medieval ages, disability was often considered a punishment from God or the work of the devil. People with disabilities were alternately shunned, condemned, or used for entertainment purposes, e.g., as court jesters. (Drum, 2009, pg. 27)
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> Within the early capitalist systems beginning to dominate Europe during the seventeenth century, the primary definition of disability was an inability to perform labor. (Nielson, 2012, p. 20)

In the 18th-20th centuries, families bore the burden of cultural expectations for what it meant to have a child with a disability. The author Kim E. Nielsen (2012) explained:

> Families always bore primary responsibility for those who could not labor and thus care for themselves –whether due to youth, old age, or mental, cognitive, or physical disabilities. Communities considered both idiots and the distracted undesirable inhabitants, particularly those without families, because of their general inability to provide for their own financial support. (p.22)

When families could not care for their loved ones with a disability, due to circumstances beyond their control, they became the wards of the community which resulted in the use of correctional institutions to warehouse such individuals. Incarceration continues to this day, and this is one of the last frontiers that needs to be changed.

(Mis)perception of Disability

The general public has historically viewed people with disabilities being dependent on others. According to the author of A Disability History of the United States, Kim E. Nielson (2012);

> As good citizens, we are to 'stand on our own two feet' and 'speak up for ourselves'…. In this version of the national story, independence is good and dependency is bad. Dependency means inequality, weakness, and reliance on others. When disability is equated with dependency, disability is stigmatized. (p. xii)

With regards to these dependencies, as found in Ingstad and Whyte (1995), Murphy asserts "…that they are universal aspects of all social relationships and that dependency is a problem that all disabled people must confront" (p. 11).

The views of dependency from the larger society regarding people with disabilities creates a disparity between the two groups. As stated by Funk in Drum et al. (2009) "…throughout time the inferior economic and social status of people with disabilities has been viewed as the inevitable consequence of the physical and mental differences imposed by disability" (p. 45).

This disparity has been further exaggerated with images in America's cultural views by the media, which created negative connotations on who or what a person with a disability looks like. For example, the March of Dimes routinely utilized images of disabled children meant to elicit pity and thus funding dollars. The authors Drum et al. (2009) shows Gartner and Joe reported such "…images of disability in literature demonstrates that these views of disability have in fact been disabling – creating a barrier even more influential than the disability itself". (p. 45) Throughout history, as found in Drum's et al. (2009) book, Ward said that "Literature, both fiction and accounts of actual fact, has often depicted persons with disabilities as beggars, heroes, and thieves" (p. 45).

Defining oneself as a person with a disability has been a challenge, as the broader community assigned names and titles to people with disabilities. These definitions have changed as views and attitudes have changed regarding people with Disabilities. Nielson (2012) says "Not only do people with disabilities, have a history, but the concept of disability has a history as well" (p. xiv).

History, demonstrated through literature, has shown the economic and social disparities experienced by people with Disabilities. The able-bodied community's social view has defined this marginalized community through its definitions, attitudes, and stereotypes. Also, by understanding how names and titles define people and how history creates attitudes, people will change how they view people with disabilities.

Disability is not Illness

Disability can sometimes result from an illness. However, many have erroneously assumed that a person with a Disability is ill. However, this is not the case, as illustrated by Nielson (2012):

> Disability can include disease or illness, but it often does not, and non-disabled people can be ill. Illness sometimes leads to disability (but it often does not), and when it does the illness can go away but the disability remains. Illness, disease and disability are not synonymous. (p. xiv)

The assumptions by the broader community regarding Disability bring up the need to provide education, training, and awareness of what it means to be a person with a Disability. Traditionally, medical professionals treated a person with a disability as if they were broken and they are widely assumed to be in need of a cure and to be fixed to achieve "wholeness". According to Ingstad and Whyte (1995), "The assumption is that we master all the outcomes; every condition can be treated and adjusted, though not all can be cured" (p. 270).

If ignorance about people with disabilities continues, then their misrepresentation as being ill or having been ill will perpetuate. The importance of educating the broader community about people with disabilities being people first, and that they live their lives like anyone else with or without adaptations is crucial to raise awareness. It must begin with society's children and the adults who teach them through family discussions and classroom lectures about how to interact with people with disabilities in everyday activities.

It may start with an attitude as expressed by Murphy in Ingstad and Whyte (1995); "The physically impaired often arouse, in varying degrees, revulsion, fear, and outright hostility – sentiments that appear to be spontaneous and 'natural' because they seem to violate our values and upbringing. But do they?" (p. 153). Such attitudes are reinforced by parents. "Children are taught not to point, stare, or mention the impairments of people they meet. And so, we are treated to the paradox of nobody 'seeing' the one person in the room of whom they are acutely, and uncomfortably aware" according to Murphy in Ingstad and Whyte (1995) (p. 9).

Another way that the larger society expresses and perpetuates attitudes towards people with Disabilities, Murphy in Ingstad and Whyte (1995) gives an example in the following:

> Children are quite understandably curious about disabled people and often stare at them, only to have their parents yank their arms and say "don't look". Nothing could better teach a child to be horrified by disability; that the condition is so terrible that one cannot speak about it or even look at it. Children are in many ways taught to regard impairment with a loathing far be yond that of racial prejudice. It is a sentiment that reinforces the fear that this could happen to them. (p. 153)

How do they see people with Disabilities as "normal"? Normalizing people with Disabilities means achieving the understanding that there is nothing to fear and the knowledge that people with Disabilities are human. Recent factors such as the Americans with Disabilities Act legislation and more positive media portrayal of people with Disabilities, and improved dialogue with the Disability community have decreased, directly or indirectly, the negative attitudes and exclusion of people with disabilities. Dialogue with persons with Disabilities will increase knowledge of how they acquired their disability, how they live their lives, and how the Disabled person has experienced discrimination and oppression. The broader community's awareness would empower the life of a person with a Disability at home, at work, at school, and during recreational pursuits. When there are allies, friends, and family that interact with Disabled people in positive ways, this creates an enriched life for all.

Impairment vs. Disability

The World Health Organization (WHO) website page on Disability and Health (2018) defines Disability using the International Classification of Functioning, Disability and Health (ICF), which defines disability as "…an umbrella term for impairments, activity limitations and participation restrictions. Disability is the interaction between individuals with a health condition (e.g. cerebral palsy, Down syndrome and depression) and personal and environmental factors (e.g. negative attitudes, inaccessible transportation and public buildings, and limited social supports)" (p. 1). This is an improvement from previous definitions. In 1980, at the World Health Assembly in Geneva developed a paper on the International Classification of Impairments, Disabilities, and Handicaps which includes a definition focusing on the medical model, as in what is missing in the person's ability to function in their environment; "An impairment defined as any loss or abnormality of psychological, physiological, or anatomical structure of function" (p. 27). The fact that there have been changes in 38 years of the definition of impairment to Disability means that American society has had a dialogue with the Disability community. Previously definition of Disability had impairment as the primary focus, and now it is a subsidiary of the whole picture that includes the primary focus on barriers one faces in their environment.

There is another view to consider. If a person with a Disability is proud of who they are and of belonging to a larger Disability community, they should express it from an aesthetic point of view. They would define what it means to be a person with a Disability using the concept of big 'D' vs. little 'd.' The person with a "disability" may view themselves as being part of a disempowered minority. They may see themselves as belonging to the medically defined category of "the disabled." The broader and very proud "Disability" community member would use the capital "D" and only use the lowercase "d" from a medical point of view. A person with a Disability conveys pride in one's Disability and has embraced their shared history, experiences, and awareness of who they are as a "people."

The medical community has a history of attempting to define who Disabled people are when it is the individual with a Disability who should define themselves. Nielson (2012) sums up the issue; "…the historical reality that being defined as disabled has made access to power and resources limited or difficult: and that hierarchies of power contribute to definitions of disability" (p. xv).

Definition of Handicap

Disability historians define the term, "Handicap" as a person with a disability allowed to beg with their cap in hand (hand in cap later became handicap). Historically, people with disabilities had to beg because of very few job opportunities for them. At one time, these people had to be granted "the right to beg." "Sending disabled family members onto the street to beg gives an immediate return; apprenticing them requires an investment of money that the family may not have. Beggars use their impairment as a tool to work for their families…" (Ingstad & Whyte, 1995, p. 18). Today, people within the Disability Community prefer not to have this term used in relation to themselves.

Ableist Attitudes

Attitudes are stigmatizing. They "put people in their place" so that one can feel safe or better about themselves. An assumption is based on observations from personal experience. The primary use of attitudes by the majority result in discrimination that minority groups experience. The Disability community experiences an ableist attitude by others who can walk, talk, see, hear, move and think without adaptive equipment or modification(s) of their environment. As explained by the author Nielson (2012):

> Ideologies and practices that belittle and/or limit people with disabilities arise from ableist attitudes. Ableist attitudes are those that reflect a fear of, aversion to, or discrimination or prejudice against people with disabilities…. Like racism, sexism, or homophobia, ableism is directed at individuals and built into social structures; it is lived out purposefully, accidentally, and unknowingly. (p. xvi)

Attitude is the way they think and feel that results in behavior that potentially limits a person with a Disability from fully participating in society. In Drum et al. (2009) book Bickenback argued that "the limitations people with disabilities face in education, employment, housing and transportation are not the products of their medical condition, but of social attitudes of neglect and stereotypical images about their capacities and needs" (p. 34).

Interactions Between People with and without Disabilities

It is essential to understand how interactions between the able-bodied and the Disabled have occurred historically to improve opportunities and productive discussions in the present. Most people would not have had an opportunity or a willingness to interact with a person with a Disability. If there could be more opportunities, then the awkwardness of the communication process would lessen. Ingstad & Whyte (1995) explain more about this awkwardness:

> There is deep and uneasy ambivalence in relations between the able-bodied and the disabled, for how is one supposed to act toward a quasi-human, a person who literally arouses fear and loathing…. Meetings between the able-bodied and the disabled can indeed be awkward, tense, and indeterminate affairs…. The disability – paraplegia, blindness, or whatever it may be --- is at center stage, in the forefront of the consciousness of both parties, and both must take steps to normalize the meeting… (p. 144)

Davis states in Ingstad and Whyte book (1995) that "the first problem is where to direct your eyes" (p. 148). There are rules of eye contact that are important in the Disability community. The Deaf need eye contact to get additional information from the conversation that they cannot hear. The person who uses a wheelchair prefers to see the eyes of the person they are speaking to rather than their stomach. A person with a cognitive or mental Disability prefers to have eye contact to be recognized as a person with dignity.

One of the biggest problems that people with disabilities have is the isolation factor, which results from a lack of awareness that people with disabilities are social beings like all humans. Isolation of the disabled is a problem for both the abled and the disabled as "Isolation is a two-way street" as stated by Murphy in Ingstad and Whyte (1995) (p. 149). The way to rectify this is to talk to people with disabilities as they would with anyone else. When they become a part of each other's lives, this will reduce both parties' isolation and awkwardness and make interactions much more effective and humane.

The Newly Disabled

When one is newly disabled, they may go through an identity crisis. Their ability to adapt to this change depends on their background, experiences, and resiliency. A personal account looks like this: "I was not yet ready to identify fully with the disabled… Research among the motor-handicapped and participation in their organizations forced me to see myself in their lives, and this left me feeling that my own status was insecure and threatened…" as stated by Murphy in Ingstad and Whyte (1995) (p. 150). There is a relationship between social standing and disability, especially for those who are newly disabled and there is a process of self-discovery involved.

Conclusion

The information on Disability Awareness in this paper encompasses the following; Disability Culture and Community, Definitions, Attitudes, Interactions with People with Disabilities, the Newly Disabled and Disability History. Each topic presented provides background information to support the reader in becoming a better mentor, educator and employer. It is vital to have a Disability-inclusive mentoring program. Further study in this field will provide future mentors the opportunity to be more effective in their field of work.

The Disability community has evolved and changed through the centuries in the face of adversity. It is important as mentors, educators, or employers to have an awareness of Disability culture and history. This will facilitate a dialogue on what is needed to create change towards equitable opportunities. People with Disabilities, working with allies to increase access to social, educational and employment areas, can contribute new ideas that create beneficial change for all.

References

Bickenbach, J.E., (1999). Models of disablement, universalism and the international Davis, F., (1961). Deviance disavowal: The management of strained interaction by the visibly handicapped. SociNo table of figures entries found.al Problems 9:121-132.

Disability and health. (2018, January 16). World Health Organization. Retrieved June 26, 2020, from https://www.who.int/news-room/fact-sheets/detail/disability-and-health.

Drum, C.E., (2009). Models and approaches to disability. In Drum, C.E., Krahn, G.I., & Bersani, H. (Eds.), Disability and public health (pgs 27 – 44). Washington D.C.: American Public Health Association.

Drum, C.E., Krahn, G.I., & Bersani, H. (Eds.), Disability and public health. Washington D. C.: American Public Health Association.

Funk, R., (1987). Disability rights: from caste to class in the context of civil rights. In Gartner, A., & Joe, T. (Eds.), In images of the Disabled; Disabling images. New York: Praeger (1987).

Gartner, A., & Joe, T., (Eds.), (1987). Images of the Disabled; Disabling Images. New York: Praeger.

Ingstad, B. & Whyte, S.R., (Eds.), (1995). Disability and culture. University of California Press.

Murphy, R.F., (1987). The body silent. (pgs. 156). New York: Henry Holt

Murphy, R.F., (1995). Encounters: The body silent in America. In Ingstad, B. & Whyte, S.R. (Eds.), Disability and culture. (pgs 140 – 158). Berkeley and Los Angeles: University of California Press.

Murphy, R.F., Scheer, J., Murphy, Y., Mack, R., (1988). Physical disability and social liminality; A study in the rituals of adversity. Social Science and Medicine 26(2): 235-242.

Nielson, Kim E., (2012). A disability history of the United States. Boston, Massachusetts: Beacon Press.

Ward, M.J., (2009). A personal perspective on historical views on disability. In Drum, C.E., Krahn, G.I., & Bersani, H. (Eds.), Disability and public health (pgs 45 – 64). Washington D.C.: American Public Health Association.

Whyte, S.R., (1995). Disability between discourse and experience. In Ingstad, B. & Whyte, S.R. (Eds.), Disability and culture. (pgs 267 – 291). Berkeley and Los Angeles: University of California Press.

Whyte, S.R., & Ingstad, B., (1995). Disability and culture: An overview. In Ingstad, B. & Whyte, S.R. (Eds), Disability culture. (pgs 3 – 32). Berkeley and Los Angeles: University of California Press.

World Health Organization, (1980). International Classification of Impairments, Disabilities, and Handicaps. Geneva: World health assembly. (pg. 27)